

Experiences of augmented arm rehabilitation including supported self-management after stroke: a qualitative investigation

Author names and affiliations:

Stefanie Schnabel^a, Frederike van Wijck^b, Brenda Bain^c, Mark Barber^d, Philippa Dall^e, Alexander Fleming^f, Andrew Kerr^g, Peter Langhorne^h, Alex McConnachieⁱ, Kathleen Molloy^f, Bethany Stanley^j, Heather Jane Young^k, Lisa Kidd^l

^a Centre for Living, School of Health and Life Sciences, Glasgow Caledonian University, Cowcaddens Road, Glasgow G4 0BA. Email: Stefanie.Schnabel@gcu.ac.uk

^b Centre for Living, School of Health and Life Sciences, Glasgow Caledonian University, Cowcaddens Road, Glasgow G4 0BA. Email: Frederike.vanWijck@gcu.ac.uk

^c Centre for Living, School of Health and Life Sciences, Glasgow Caledonian University, Govan Mbeki Building, Cowcaddens Road, Glasgow G4 0BA. E-mail: Brenda.Bain@gcu.ac.uk

^d Medicine for the Elderly and Stroke, NHS Lanarkshire, University Hospital Monklands, Monkscourt Avenue, Airdrie, ML6 0JS, E-mail: Mark.Barber@nhs.net

^e Centre for Living, School of Health and Life Sciences, Glasgow Caledonian University, Govan Mbeki Building, Cowcaddens Road, Glasgow, G4 0BA, E-mail: Philippa.Dall@gcu.ac.uk

^f Different Strokes, Different Strokes Central Services, 9 Canon Harnett Court, Wolverton Mill, Milton Keynes, MK12 5NF, E-mail: info@differentstrokes.co.uk

^g Bioengineering, University of Strathclyde, Wolfson Building, 106 Rottenrow East, Glasgow, G4 0NW, E-mail: a.kerr@strath.ac.uk

^h Geriatric Medicine, 3rd Floor, Centre Block, Royal Infirmary, Glasgow, G4 0SF. Email: pl11m@clinmed.gla.ac.uk

ⁱ Robertson Centre for Biostatistics, University of Glasgow, Boyd Orr Building, University Avenue, Glasgow, G12 8QQ, E-mail: alex.mcconnachie@glasgow.ac.uk

^j Robertson Centre for Biostatistics, University of Glasgow, Boyd Orr Building, University Avenue, Glasgow, G12 8QQ, E-mail: bethany.stanley@glasgow.ac.uk

^k Centre for Living, School of Health and Life Sciences, Glasgow Caledonian University, Cowcaddens Road, Glasgow G4 0BA. Email: heatherjaneyoung@yahoo.com

^l School of Medicine, Dentistry & Nursing, College of Medical, Veterinary & Life Sciences, University of Glasgow | 57-61 Oakfield Avenue, Glasgow, G12 8LL. Email: Lisa.Kidd@glasgow.ac.uk

Abstract

Objective: To explore the experiences of stroke survivors and their carers of augmented arm rehabilitation including supported self-management in terms of its acceptability, appropriateness and relevance.

Design: A qualitative design, nested within a larger, multi-centre randomised controlled feasibility trial that compared augmented arm rehabilitation starting at three or nine weeks after stroke, with usual care. Semi-structured interviews were conducted with participants in both augmented arm rehabilitation groups. Normalisation Process Theory was used to inform the topic guide and map the findings. Framework analysis was applied.

Setting: Interviews were conducted in stroke survivors' homes, at Glasgow Caledonian University and in hospital.

Participants: 17 stroke survivors and five carers were interviewed after completion of augmented arm rehabilitation.

Intervention: Evidence-based augmented arm rehabilitation (27 additional hours over six weeks), including therapist-led sessions and supported self-management.

Results: Three main themes were identified: (1) acceptability of the intervention (2) supported self-management and (3) coping with the intervention. All stroke survivors coped well with the intensity of the augmented arm rehabilitation programme. The majority of stroke survivors engaged in supported self-management and implemented activities into their daily routine. However, the findings suggest that some stroke survivors (male >70 years) had difficulties with self-management, needing a higher level of support.

Conclusion: Augmented arm rehabilitation commencing within nine weeks post stroke was reported to be well tolerated. The findings suggested that supported self-management seemed acceptable and appropriate to those who saw the relevance of the rehabilitation activities for their daily lives, and embedded them into their daily routines.

Introduction

Stroke is a leading global health problem and a major cause of disability in adult life.¹ It is estimated that arm impairment affects over 70% of acute stroke survivors,² half of whom still have reduced arm function at six months post stroke.³ This has an impact on activities of daily living, well-being and health-related quality of life.⁴ Arm function may be improved through repetitive, functional task practice, however the dose required (at least 20 hours more than usual care)⁵ is difficult to deliver within existing health resources. Therefore, stroke survivors may need to engage in self-managed rehabilitation.

Self-management has been adopted by UK national clinical guidelines for stroke.⁶ A qualitative study which investigated the factors influencing self-management after stroke found that *support* for self-management was crucial including the following key features: involvement of health care professionals, appropriate resources and the role of informal carers.⁷ The idea of supported self-management in stroke and other chronic diseases is gaining prominence⁸, however little is known about the expectations and experiences of stroke survivors and their carers who engage in supported self-management as part of arm rehabilitation. Only one study has explored the experiences of stroke survivors of arm rehabilitation, using a non-immersive virtual reality system, in a clinical setting.⁹ Stroke survivors were motivated to practise intensively, which was supervised by a therapist, and the overall experience was positive. However the acceptability of the intervention in terms of timing, dose, relevance and appropriateness was not explored.⁹

Supported self-management is also likely to confer a burden on patients and their carers.^{10,11} Therefore, further investigation is needed into how best to support self-management and to minimise the treatment burden.^{8,11} Normalisation Process Theory is concerned with the work people do to implement, embed and integrate new interventions into a daily routine,^{11, 12} and has been applied to understand the work that stroke survivors do to implement and embed supported self-management.¹¹

There is a particular need for more insight into how stroke survivors experience their engagement with rehabilitation in order to understand how their rehabilitation and self-management support needs can best be met.¹³ Augmented arm rehabilitation after stroke is one area of stroke management which is prone to treatment burden, as more self-managed

treatment may be necessary to improve outcomes. This study aimed to explore the experiences of stroke survivors and their carers of an augmented arm rehabilitation programme including supported self-management, in terms of its acceptability, appropriateness and relevance.

Methods

This was a qualitative study. The COnsolidated criteria for Reporting Qualitative Research (COREQ)¹⁴ standards were followed.

The study was conducted between March 2016 and October 2018. It was nested within the *Early VERSus Later Augmented Physiotherapy compared with usual upper limb physiotherapy (EVERLAP): a feasibility randomised controlled trial of arm function after stroke*. This was a mixed methods, randomised, multi-centre trial (Clinical Trial Registration number: ISRCTN 32522341).

Ethical approval was granted from the National Research Ethics Service (REC Reference 14/WS/1136), NHS Research & Development departments and Glasgow Caledonian University's School of Health and Life Sciences Ethics Committee. The study was funded by the Charitable Trust of the Chartered Society of Physiotherapy (N/12/10) and the sponsor was Glasgow Caledonian University.

The EVERLAP study focused on exploring the feasibility of a definitive randomised controlled trial comparing Early and Later augmented arm rehabilitation with usual care. Information about the EVERLAP study is reported in detail elsewhere.¹⁵ Briefly, stroke survivors were randomised into one of three groups; the Early group (starting augmented arm rehabilitation three weeks post stroke, together with usual care), the Later group (starting nine weeks post stroke, together with usual care) or the usual care only group. The content of the intervention comprised a manual of routinely available physiotherapy interventions, aimed at improving meaningful functional activity of the affected arm, based on current best evidence. This included treatment strategies for priming, augmenting and practising functional skills. Study physiotherapists formulated a patient-centred treatment plan for each participant, taking into account their needs, goals and abilities, current best evidence

and their clinical judgement. The target dose of augmented arm rehabilitation was an additional 27 hours of arm rehabilitation (45 minutes each day, six days per week over six weeks). These additional 27 hours included face-face time with the study physiotherapist, as well as time undertaking supported self-management, with their proportion tailored to each individual. Stroke survivors could choose between a booklet with activities or a mobile phone reminder to supplement their supported self-management. The primary outcome was the Action Research Arm Test at 24 weeks and a tool kit of secondary outcomes included measures of impairment, activity limitation and participation restriction.¹⁵ The aim of this qualitative study was not to compare the Early and Later groups, but to explore the experiences of participants in both these groups.

All study participants gave written informed consent for their participation in an exit interview after the end of the augmented arm rehabilitation programme to discuss their experiences with a researcher, who was otherwise not involved in the study. The anonymity of all stroke survivors and their carers was protected by using unique identification numbers for all transcripts, and false names were given for publications and presentations.

The inclusion criteria for this qualitative study followed the eligibility criteria for stroke survivors and their carers (if available) in the EVERLAP study.¹⁵ In addition, all stroke survivors (including anyone with aphasia), who had completed the augmented arm rehabilitation (from either the Early or Later group) and were willing to take part in an interview were invited to this qualitative study. A convenience sampling approach was used. Stroke survivors who had been part of the usual care group were not interviewed as the purpose was to understand more about the acceptability of the augmented intervention. Stroke survivors who did not complete the programme were not interviewed because it was felt that it would not be appropriate to contact those who had withdrawn, as the most common reason for withdrawal was being unwell or unwilling to continue.

Stroke survivors and carers were approached by the study physiotherapist once they had completed the EVERLAP intervention to arrange the interview. Interviewing stroke survivors together with their carers was selected for several reasons: firstly, some carers played a role in supported self-management. Also, carers could potentially add detail to what stroke survivors did during their supported self-management, and add their perspective. Another

benefit of paired interviews is that they may complement one another in the storytelling and the observation of non-verbal communication can add valuable insight.¹⁶ Carers can also be the voice for the participant in the interview when speech impairment is a problem.¹⁷ Carers who did not consent but were present during the interview were made aware that their contributions were recorded and transcribed but could not be included in the analysis of the findings.

Semi-structured interviews with stroke survivors and their carers (if present) took place in stroke survivors' homes, at the University, or in hospital, between September 2016 and April 2018 following a topic guide (Appendix 1). Interviews were audio recorded and transcribed verbatim by a transcriber who was otherwise not involved in the study.

The work of May et al.¹² and Murray et al.¹⁸ was used to guide the application of Normalisation Process Theory in this study. Normalisation Process Theory was used to inform the topic guide and the analysis of the study findings.^{12,18}

The four main constructs of Normalisation Process Theory and how they were incorporated into the topic guide for this study were as follow:

Coherence (sense-making work): Do stroke survivors and their carers understand the condition and what can be done to manage the impact of their stroke?

Cognitive participation (relationship work): Are stroke survivors and their carers engaged and committed to the augmented arm rehabilitation programme and supported self-management?

Collective action (enacting work): Do stroke survivors and their carers make use of all opportunities of the augmented arm rehabilitation programme? What is acceptable and what is not acceptable to them?

Reflexive monitoring (appraisal work): Do stroke survivors and their carers reflect on the relevance and appropriateness of the augmented arm rehabilitation programme and how it can be tailored to their needs?

The following areas were probed in relation to the constructs of Normalisation Process Theory:

- 1) Life after stroke
- 2) Experience with the content, intensity, duration and timing of the augmented arm rehabilitation
- 3) Impact of the intervention on arm function
- 4) Relationship with the health professionals (study and usual care physiotherapists)
- 5) Impact of the intervention on quality of life
- 6) The role of the carer in the augmented arm rehabilitation programme.

The topic guide was piloted (the data were not included in the analysis) with two stroke survivors who were also involved in the design of the EVERLAP study. The topic guide was iteratively refined throughout the interview process to identify further areas for probing/discussion in subsequent interviews.

Data saturation was achieved after interview number 15 but two more interviews were conducted and no new data emerged. Interviews ranged in length between 16 min. and 71 min. (median 39 min.).

During data collection and analysis a reflexive approach was adopted. Field notes were taken for each interview and used to supplement the data collection, to describe the context in which the interviews took place and the researchers' own feelings during field work.¹⁹ The interviews were undertaken by two researchers, including the first author. As physiotherapists, both interviewers had experience working in the health service with stroke survivors. The interviewers were not directly involved in the recruitment to or the delivery of the EVERLAP intervention. The participants were aware that the interviewers were involved in the wider EVERLAP study and that the interviews were part of the first author's PhD study.

Framework analysis was used to analyse the transcripts²⁰, which was regarded as the most appropriate approach because it provided a systematic structure to manage and interpret a rich data set. The transcripts were analysed according to the six steps of framework analysis: familiarisation, constructing an initial framework, indexing and sorting, reviewing data extracts, data summary and display, and description.²⁰ Data were managed using the software NVivo11. All identifiable data (names, places) were removed from the transcripts. Audio recordings were listened to, transcripts were read repeatedly and a coding framework

was established. The coding framework was further refined with each transcript read. For each emerging theme a matrix was created which had several subthemes. The first author and co-authors (chief investigator of the EVERLAP study (FvW) and experienced qualitative researcher (LK)) were involved in the coding. Themes were discussed at different stages during the process of analysis and final themes were agreed. During the abstraction and interpretation stage, categories were developed and linkage between themes identified.²⁰ Framework analysis was underpinned by the main principles of Normalisation Process Theory, to which the findings were mapped.

Results

Stroke survivors were recruited for the EVERLAP study from six different hospitals in Scotland.

A total of N = 39 stroke survivors (Early and Later group) and N = 10 carers (those who consented) were eligible to take part in the interviews. N = 7 stroke survivors (N = 1 carer) from the Early group and N = 10 stroke survivors (N = 4 carers) from the Later group took part in the interviews. Therefore a total of 17 stroke survivors and five carers (those who consented) were interviewed (six females, age range 40-84 years). The other stroke survivors were interviewed alone or had carers present who did not consent. Three stroke survivors with aphasia were interviewed, where only one carer was available for the interview.

A total of N = 22 were not available for the interview for the following reasons: N = 3 were lost to follow-up, N = 10 discontinued with the intervention (including N = 5 who were not well enough to continue, N = 3 who were not willing to continue, N = 1 died and N = 1 was discharged to location outside catchment area) and N = 9 declined the interview (including N = 2 who felt they had too much to cope with, N = 1 declined due to aphasia and N = 6 did not give a reason).

The demographics of stroke survivors who participated in the interviews are shown in Table (1).

[Table 1 about here]

The mean (SD) total amount of therapist-led augmented time per participant was 4h. 3 min. (2h. 44 min.) in the Early group and 5h. 16 min. (3h. 6 min.) in the Later group, which was the maximum dose of face-face physiotherapist time that could be delivered.

During the analysis, three main themes were identified: (1) acceptability of the intervention (2) supported self-management and (3) coping with the intervention. The following section presents the themes and subthemes and quotes from stroke survivors and carers. The study findings were interpreted through the lens of Normalisation Process Theory. Table (2) gives an overview of how the subthemes align with the constructs of Normalisation Process Theory. Carers of stroke survivors are referred to using the letter 'C' followed by their false name. The Early and Later augmented therapy groups to which stroke survivors were randomised are referred to using the letters 'EG' and 'LG' and followed by the age of the participant (age not included for carers).

[Table 2 about here]

Acceptability of the intervention

All stroke survivors and their carers felt positive about the augmented arm rehabilitation programme. All stroke survivors liked the intensity of the arm rehabilitation, the supportive nature of their interaction with the study physiotherapists, while the majority liked the opportunity to engage in supported self-management.

Most stroke survivors reported that activities undertaken with the study physiotherapist and practised through supported self-management in their own homes were relevant to their daily lives and helped with managing the paresis and sensory impairment of the affected arm. The majority of stroke survivors said that the activities had a practical focus and regarded this as a positive aspect. Activities that were tailored to stroke survivors' needs and real-life activities that were meaningful to their daily lives, such as practising throwing a ball for people with small children or dogs, were perceived as being particularly

valuable. Stroke survivors also appreciated that the activities were built on what was done the day before, challenging them a bit further. This is an example of *coherence* as well as *cognitive participation*, where stroke survivors and their carers tried to improve their understanding of the condition and engage in the management of the arm impairment after stroke.

'... it [EVERLAP] was very much a practical focus for the exercises ... So that not only was he doing the exercises but there was a purpose involved to perform the exercises.' (C of Timo, LG)

For one stroke survivor the EVERLAP activities helped her to look after her young baby again.

'This month I have been looking after him [young son] myself so it [the strength] is building up.' (Lydia, EG, age 40 years)

One of the stroke survivors however felt that the exercises were not optimally tailored to his needs, reporting that:

'More exercises for fine motor skills would have helped me more.' (Peter, LG, age 64 years)

All stroke survivors valued the physiotherapist-led sessions and felt that the human contact was vital because they needed someone to supervise the exercises, to give guidance and support. The study physiotherapists also acted as a motivator to some stroke survivors and others praised the supportive nature of their relationship. This aligns with the Normalisation Process Theory construct *collective action*, which reflected on the opportunities created through the augmented arm rehabilitation and finding out what is acceptable and not acceptable to them as part of the therapist-led sessions.

'[The EVERLAP PT] was very very supportive and didn't em... even if you don't feel like the exercising you know the EVERLAP PT is coming and em... it is good em...she would just be very motivational.' (Timo, LG, age 49 years)

'So I suppose the human contact and the supportive relationship as I saw it was important and helpful to me.' (Peter, LG, age 64 years)

'... the Study physiotherapist was a positive influence on me. When I was em ... feeling down em ... she said like I am doing really well and stuff' (Lydia, EG, age 40 years)

All stroke survivors and their carers felt that the intensity of the EVERLAP intervention was acceptable and well tolerated. Those stroke survivors and carers who engaged in supported self-management reported that they coped well, implementing the 45 minutes of exercise into their daily routine, and did not see it as a burden.

'The more the merrier. The intensity suits me.' (Simon, LG age 65 years)

'Oh yeah it was good. It was intensive it really helped.' (C of Simon, LG)

'The more you can encourage people to do things the better.' (Anthony, LG, age 56 years)

In terms of the duration of the EVERLAP programme, the views of the stroke survivors were more variable. Several of the stroke survivors and their carers felt that six weeks of augmented arm rehabilitation was sufficient as they felt that the study physiotherapists had shown them most exercises and were not sure if a longer duration would have resulted in any further improvements. Some reported that six weeks was not long enough and they suggested that rehabilitation programmes should be extended to 12 weeks, as they needed more direct support from therapists. Only one felt that the programme should have been a bit shorter.

'I think that was also the time to stop because I think any more em ... improvements I am not sure if it would' *'I think it was perfect it was just enough.'* (Timo, LG, age 49 years)

'... we did six weeks where we could have done with 12...you would em ... benefit better the longer you got working with the likes of the study physiotherapist.'

(Lewis, LG, age 75 years)

In terms of the timing of the EVERLAP programme, the views of the stroke survivors were similarly divided. Most stroke from the Later group reported that it was ideal timing for them, whereas some participants in this group reported that they would have liked to begin earlier after their stroke. In the Early group, many felt that beginning the EVERLAP programme early after their stroke had a positive impact on their recovery. This subtheme is an example of *reflective monitoring* because stroke survivors and their carers reflected on the intensity, duration and timing of the intervention and gave feedback on what could be improved for a future study.

'I could have done with them earlier.' (Thomas, LG, age 72 years)

'It kicked in at the right time. Because [Timo] had gained more strength.' (C of Timo, LG)

All stroke survivors felt that the EVERLAP programme had a positive impact on their life and recovery after stroke. The augmented arm rehabilitation programme helped some stroke survivors to set and achieve their personal objectives. It was also reported that the intervention itself and the presence of the study physiotherapists had a positive impact on mood and motivation. There were no negative aspects reported. This subtheme also mirrors *reflective monitoring* as stroke survivors reflected on the relevance of the intervention to their recovery.

'EVERLAP helped to set objectives. ... So it was good for me I think because the danger ... would have been ... but get a bit lazy kind of thing and maybe sit too much I just felt there was positivity to it.' (Peter, EG, age 64 years)

'It's the mental attitudes and the knowledge of how to get better.' (Sean, LG, age 68 years)

'I enjoyed them coming and I felt it was much more practical than anything I received in the hospital ... maybe because they were in my house and they knew what I was having to put up with.' (Maureen, LG, age 72 years)

Supported self-management

Supported self-management practice that was encouraged as part of the therapist-led sessions was reported to be valuable. It helped stroke survivors to feel in control of their rehabilitation progress and provided a focus after discharge from

'... the very closed and supportive environment in the hospital ... ' (Peter, LG, age 64 years).

The majority of stroke survivors reported that they engaged in supported self-management every day or most days and had established a routine for doing the exercises. They reported on integrating supported self-management into a daily routine so that exercising did not feel like a burden to them. However, three out of four stroke survivor participants who were male and over the age of 70 reported that it was easier for them to engage in the exercises when the study physiotherapist was present but that they did not do so when they were on their own at home. Engagement in supported self-management aligns with *cognitive participation* and showed how engaged and committed they were in this.

'A [small] bit and often and I can feel the benefit. ... I don't like exercise[s] but I have got to do it so I just try and build on it to achieve my daily routine.' (Timo, LG, age 49 years)

'But it [engaging in self-management] was basically a constant thing. ... it all became part of my day.' (Chris, LG, age 56 years)

However, some stroke survivors reported that they engaged in supported self-management every couple of days, feeling that they did not cope with all the activities or the supported self-management.

'I coped with some of them [exercises]. Some of them I couldn't do.' (Simon, LG, age 65 years)

'I managed the exercises alright when the EVERLAP PT was there.' *'All the exercises were good at the time. But em ... well I am not doing them anymore and em ... em ... and just nothing else is happening.'* (Lewis, LG, age 75 years)

Several stroke survivors reported that they were self-motivated to engage in exercises themselves. Most motivation was related to specific goals such as acquiring better dexterity or *'wanting to get better'* (Chris, LG, age 56 years) in general. Other motivators to engage in supported self-management appeared to be a desire to return to work, caring responsibilities for young families or for grandchildren. *Motivation for supported self-management* aligns with *coherence* as stroke survivors and their carers understood what can be done in rehabilitation to achieve their goals such as returning to work.

These findings are illustrated by the following quotes:

'My hand and my brain are my tools of work so I need this [referring to hands and brain] working ... I can't accept I'm not being able to write or type and that's how I have to work on these. The self-motivation for me is to get back to work. ... So I have got cars to pay, I have got a house to keep I have got a boy to put through school and things like that. I need to get back to work and that's my motivation.' (Anthony, EG, age 56 years)

'I don't like exercises generally but I had a problem ... she [the EVERLAP PT] would just be very motivational.' (Timo, LG, age 49 years)

'I practised as much as possible. I have always been that way I [cannot] sit and sit and sit I have got to do something' (Ross, LG, age 63 years)

'Em ... looking after my son. Playing with himSo em ... I can take him [my son] full time.' (Lydia, EG, age 40 years)

Here, stroke survivors and their carers talked about the suitability of supported self-management in addition to therapist-led sessions at that stage of their recovery. Most felt that this was acceptable. A few stroke survivors felt overwhelmed with being asked to undertake exercises independently and wished for more therapist-led sessions as discussed in the previous section. This is an example of *reflective monitoring* because stroke survivors reflected on how appropriate supported self-management was at that point in time of their rehabilitation and where modification was necessary such as needing more input from therapists.

'So [yes] the more you can encourage people to do things the better. ... the sooner you start these things the better.' (Anthony, LG, age 56 years)

'If you don't do it [the exercises] you will stiffen up so it [the exercises] did help.'
(Ross, LG, age 63 years)

It was often reported that tiredness, self-reported 'laziness', pain and other commitments such as engaging with visitors or home helpers imposed barriers to supported self-management. A facilitator for engaging in supported self-management was the exercise booklet and the mobile phone reminder, which was offered to everyone in the study. The majority used the exercises booklet and some (one from each of the Early and Later group) used the mobile phone reminder. One user of the mobile phone reminder and his carer reported that the reminder helped him considerably in doing the activities regularly. Others felt they were motivated by the study physiotherapists to do the activities. Exercising was reported as a motivation and a positive factor in their recovery after stroke. This subtheme falls into the Normalisation Process Theory construct of *collective action* as stroke survivors and their carers state what helped them most and what did not work in their rehabilitation.

'Yes. Sometimes if there's fatigue you have just got to admit you know that that's it today. Just make sure that you em ... it is not a case of em ... doing nothing it is just even if I just do something Some days you are good and some you are not so good. ... visitors kind of wipe me out.' (Timo, LG, age 49 years)

'Oh lots. Because with the phone, the phone was ideal because you could set it to, you know, there is an alarm to go off, and that is what I did. So I put in em ... I would select so many different exercises and then I did it for every hour didn't I?'
(Anthony, LG, age 56 years)

Coping with the intervention

Stroke survivors and their carers talked about what helped them to commit to the demands of the augmented arm rehabilitation, such as undertaking supported self-management and decision-making.

Several stroke survivors reported that they had a carer who was involved in their rehabilitation. The majority of those included said that their carers acted as a reminder and sometimes a controller for doing supported self-management. Most of the carers, who were available, were involved in the actual exercises such as helping with supporting the arm or monitoring the independent exercises. These findings show that the engagement and commitment of a support network is vital in the recovery after stroke, which is an example of *cognitive participation*.

'But we are getting there and I mean the support that he gets, even if he posts one of these wee videos the support he gets from TAE KWON DO, I think when he posted the first one you seen a lot of the people at TAE KWON DO didn't see him probably maybe the first month you were out of hospital you maybe weren't anywhere. But once I kind of got him to a class he would kind of walking with his feet and his stick and they were all "great to see you" and they were even mentioning as your hand was improving.' (C of Anthony, LG)

'Although as I said earlier on, sometimes I get lazy and my wife had to always remind me "have you done your exercises today" and would say "maybe or maybe not" [laughter].' (Peter, LG, age 64 years)

'Yes I help Timo once the study physiotherapist shows us what to do and she has advised me how far you can go. And which muscles can em' (C of Timo, LG)

Most stroke survivors reported that they were actively involved in the decision-making on their goals and rehabilitation plan in relation to EVERLAP whilst others were happy to let the study physiotherapists decide on the rehabilitation plan. *Being actively involved* aligns with *coherence* because stroke survivors and carers need an understanding of the condition and in the management of stroke in order to make decisions regarding their rehabilitation goals and rehabilitation plan.

'I think the study physiotherapist was really good in seeing what I would need to do more of.' (Sean, LG, age 68 years)

'But with the study physiotherapists I was very much involved in what they were doing. I am a control freak just so that you know I can't help it' (Maureen, LG, age 72 years)

Discussion

The findings from those who completed the programme and took part in the interview show that the augmented arm rehabilitation within the EVERLAP study was acceptable, relevant and meaningful to stroke survivors and their carers. The practical focus of the exercises, which were tailored to stroke survivors' abilities, needs and goals and designed to enhance the use of the affected arm in functional activities, was perceived as valuable. The importance of a practical focus in arm rehabilitation is also highlighted by Barker and Brauer²¹ who found that it was important to stroke survivors to integrate the affected arm into routine tasks.

The intensity of the intervention was regarded as positive and well tolerated, and demonstrates that at least a proportion of stroke survivors and their carers were willing to engage in treatment that was more intensive than usual care. The amount of face-to-face augmented treatment was low, however. The optimal dose of arm rehabilitation is much

debated.^{22, 23} One study provided 300 hours of arm rehabilitation over 12 weeks, respectively, but these involved mostly stroke survivors in the chronic stage.²³ Therefore it may not be possible to give an absolute recommendation for the treatment dose, as this needs to be tailored to individual tolerance and ability, and future studies should carefully explore the acceptability of therapy dose.

The timing of the intervention was perceived differently in both groups. Most from the Later group and from the Early group felt that the start of rehabilitation was acceptable to them, which may indicate that in their individual circumstances, they felt ready to engage. This study suggested that it may be difficult to give a recommendation for a standard time point that is optimal - from a service user perspective - to start with augmented arm rehabilitation after stroke.

A strategy for coping with self-managed practice was to link intervention activities to meaningful, everyday activities that stroke survivors were able to see the value of. Building these into daily routines may help to reduce the burden of finding additional time for treatment. A systematic review by Gallacher et al.¹⁰ found that physical exercises constituted treatment burden, but embedding exercises into a daily routine was a self-management strategy for coping with this burden. Integrating self-management into a daily routine is part of health behaviour change.²⁴ This may be mediated by habit formation²⁵, i.e. forming a new behaviour to ultimately develop automaticity.²⁵ Behaviour change requires self-efficacy, which impacts on motivation, goal setting and how much effort is made to achieve the goals when barriers arise²⁶ Findings from this study suggests that carers and study physiotherapists acted as motivators and helped participants to overcome difficulties in their rehabilitation, increasing their sense of 'mastery'.

Implementing activities into a daily routine seemed to be easier for those stroke survivors who were under the age of 70, who appeared more driven to recover or felt pressure from social responsibilities such as parenting or employment. In particular, those stroke survivors of working age and with families and child care duties appeared to be motivated. This resonates with other research which has found younger stroke survivors to be motivated to engage in rehabilitation, with their needs focusing mainly on parenting and employment.^{27,}

²⁸ In comparison, most of the over 70 year old males in this study appeared to be less

engaged and this could be related to being less goal driven, or experiencing concurrent mental illness. For example, Alex (EG, age 73 years) reported that he was feeling depressed. Danny was in a nursing home (EG, age 84 years), which is often associated with limited life-expectancy and less opportunity to engage in goal setting.⁶ Lewis (LG, age 75 years) was living with his wife but without children or grandchildren and seemed to have no clear focus in his life. Only Thomas (EG, age 72 years) was determined to improve movement in his affected arm. Given that the median age for stroke in the UK is 77 years²⁸, this finding is concerning.

Being in control of one's rehabilitation is also a positive factor in self-management. The mobile phone reminder helped stroke survivors to feel in control. Mclean et al.²⁹ also reported that high motivation was related to being actively involved in rehabilitation, whereas low motivation was associated with waiting for recovery. Most stroke survivors in this study were self-motivated and engaged in supported self-management whilst others who perceived more barriers to self-management were motivated by the study physiotherapists.

Results show that supportive carers and sometimes a supportive social network also influenced the motivation to play an active role in their rehabilitation. Most stroke survivors in this study had a carer available (Table 1) which, in their eyes, helped with their recovery because carers acted as a reminder and sometimes assisted with the exercises. Some stroke survivors were not receiving carer support as carers had other commitments such as work (e.g. Ross, LG, age 63 years). In a study by Galvin et al.³⁰ on carer involvement in exercise delivery after stroke, 91% of carers were found to be willing to help with the exercise delivery - but this was not implemented routinely in stroke rehabilitation, as only between 21% and 36% of carers were actually involved.³⁰ The importance of involving carers was highlighted by stroke survivors in another study by Satink et al.³¹, which found that stroke survivors valued the support from carers in their self-management. However, on the other hand family members can also inhibit stroke survivors developing self-management skills³¹, which suggests that more guidance and training may be needed for carers.

Finally, human contact with the study physiotherapists was seen as vital because of the supportive nature as well as the frequency of their visits, which provided regular guidance

and support. Lehmann et al.⁹ also found that stroke survivors engaged in intensive arm rehabilitation with a virtual reality system valued the human interaction with the therapists for their guidance and social interaction.

This study focused on stroke rehabilitation, but some of the findings may be transferable to other long-term conditions such as head injuries, spinal cord injuries, multiple sclerosis or Parkinson's disease, including the need for activities to have a practical focus and the importance of a support network.

This study has strengths and limitations. A qualitative approach allowed an exploration of stroke survivors' and their carers' experiences with augmented arm rehabilitation. Most studies on intensive arm rehabilitation to date have concentrated on outcomes. Two feasibility studies^{32,33} explored experiences of arm rehabilitation after stroke to some extent, however in a very limited way as they did not use qualitative methods. A strength of this study was that it went into much more depth about which aspects of the intervention were acceptable, appropriate and relevant for stroke survivors and their carers, using Normalisation Process Theory.

A limitation was that this study included a selective sample; participants were probably motivated to engage in augmented rehabilitation. However not everyone in the Early and Later groups completed the study and for ethical considerations those who did not complete were not involved in the interviews. Therefore, only selected findings can be reported from this study, which may not reflect what the excluded stroke survivors and their carers experienced. The numbers of carers interviewed was also low. However, carers were not the unit of recruitment in this study but supplemented stroke survivors' records. An additional limitation was that self-management activities were not logged, as no tool could be identified that was valid and feasible for this study population across study settings.³⁴ Therefore it is unclear how much supported self-management stroke survivors actually engaged in. Given that the target dose of augmented arm rehabilitation was 27 additional hours, stroke survivors were expected to undertake 22 - 23 hours of supported self-management – if they were able to. Logging the activities outside of face-face therapy sessions would provide an objective record of the type and number of activities stroke survivors actually undertook.

The findings are relevant for clinical practice in that they show that rehabilitation, including support for self-management after stroke, is acceptable to those who saw the relevance of the rehabilitation activities for their daily lives, and were able to embed them into their daily routines. The findings support the theory that supported self-management can be a positive factor and can enhance self-efficacy in stroke rehabilitation.⁶ Normalisation Process Theory could be applied to routine rehabilitation practice to optimise supported self-management, e.g. by making practitioners more aware of the alignment of self-management strategies with people's beliefs around the meaningfulness and purpose of goals (*cognitive participation and reflexive monitoring*). Normalisation Process Theory could also enable practitioners to develop a better understanding of what is important to people, so that they can recommend activities that are tailored to individuals and help them to find ways to integrate these into their daily lives.

More research is needed to explore the views of stroke survivors and their carers on arm rehabilitation to understand how best to support self-management that is not only personally meaningful and purposeful to them, but also meets their rehabilitation needs. In a future study it would be of value to explore how well rehabilitation needs are being met in more depth; how, under what circumstances and for whom. Findings from this study suggest that in particular the constructs *cognitive participation* and *reflexive monitoring* could help to answer research questions on how meeting rehabilitation needs after stroke could be optimised.

Clinical message

- Stroke survivors in this study were willing to engage in augmented arm physiotherapy before the early sub-acute phase post stroke.
- Supported self-management seemed to be more acceptable to those who understood the relevance of the activities and incorporated them into their daily routines.

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Appendix 1: Topic guide

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